

Testimony before the Senate Special Committee on Aging

July 17, 2000

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Mr. Chairman and distinguished members of the Committee, thank you for the opportunity to testify before the U.S. Senate Special Committee on Aging today. For two decades, I have served the sick and dying in Washington, DC, as a hospice, home care, and nursing home physician. I have been at it long enough to appreciate how significant it is for you to be having this hearing. Until recently, the fact that aging people inevitably die was simply swept off the agenda in public policy. The fact that we almost always become very sick before we die was seen as some sort of temporary inconvenience—we acted as if prevention and rehabilitation were all that health care policy needed to pursue. Reality is leading us to take seriously the simple fact that most of us will be elderly when we die, and that most of us will die of degenerative, disabling conditions. I am here on behalf of two organizations. Americans for Better Care of the Dying is a membership organization dedicated to public and professional education and aiming to make the end of life comfortable and meaningful for all Americans. The RAND Center to Improve Care of the Dying is a scholarly team that does research and supports quality improvement in order to provide the information necessary to shape policy and practice worthy to serve those with eventually fatal chronic illness.

Americans are likely to live for months or years with the diseases that eventually kill us -- and most of us will suffer from the inadequacies of a health care system that simply was never designed for people like us. Nor could it have been: from the perspective of most of the last century, a long and mostly healthy life would have seemed accomplishment enough. Changes in Americans' experience of illness and death during the twentieth century were truly astonishing. (See Table below from *Improving Care for the End of Life: A Sourcebook for Health Care Managers and Clinicians*, forthcoming from Oxford Univ. Press). The debates that shaped Medicare in the 1960's featured many patients who could not save up money for a surgery—but

very few who were suffering from long-term, implacably progressive, eventually fatal chronic illness. The care system reflects this--it was well-designed to ensure that surgery was readily available, but it simply did not anticipate the needs of people who would require medications and home health aides as they faced an eventually fatal chronic illness.

A Century of Change		
	1900	2000
Age at Death	46 years	78 years
Leading Causes of Death	infection accident childbirth	cancer heart disease stroke/dementia
Usual Place of Death	home	hospital
Most Medical Expenses	paid by family	paid by Medicare
Disability Before Death	not usually	>4 years, on average

We are learning to do better. When I first started working in hospice in 1978, most cancer patients came to hospice with terrible pain and had never been given any opioid medication (narcotics). Today, that would be scandalous. Some cancer patients still don't get adequate pain treatment, but virtually all have elementary use of opioids. In 1976, our society framed the request of Karen Quinlan's parents to stop her ventilator as a question of whether she might be said to have the "right to refuse treatment." Now, no one doubts that every patient has that right. Indeed, California and probably the United States Supreme Court have given patients the right to relief of pain. We are asking different questions, such as: "How do we arrange services so that people can count on good care? How can we train providers so that excellent care at the end of life is readily and reliably available? How do we empower patients and

families to ask for the kind of care they need, and to expect no less?" I will sketch the answers to these questions later in my testimony.

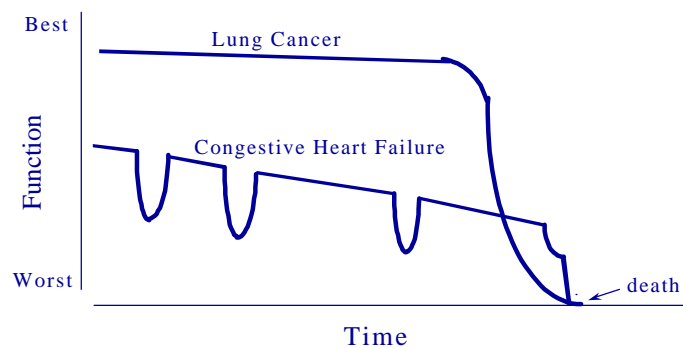
We have much to learn; we are new at this endeavor. Some insights will come from basic science research--better medications, for example. However, our most pressing need is to use what we already know about relieving suffering. The person in pain today does not have to wait for a better drug to be developed--he just needs someone to prescribe correctly what we already have! The person who wants to die at home needs no new device--she just needs the community to figure out how to get supportive services to her at home. As the report *Approaching Death* from the Institute of Medicine recommended, "Physicians, nurses, social workers, and other health professionals must commit themselves to improving care for dying patients and to using existing knowledge effectively to prevent and relieve pain and other symptoms."

Indeed, what we most need is to learn how to ensure quality, reliability, and efficiency. That takes public and professional education, changes in services and arrangements, and higher standards. In our book for the public, *The Handbook for Mortals*, for example, we instruct patients and families on how to get good pain management by giving them a comforting mini-course on what to expect, how to ask questions, how to counter errors, and how to adjust medications. In just a dozen pages, with sample words to try out, patients can know enough to start to act as colleagues in managing their situation. We also help patients understand how to make advance care plans that make a difference, how to navigate the care system, and how to pay attention to family and spiritual issues.

Some of our problems as a community arise from the persistence of old conceptions and categories. While we are still learning how to think about our new circumstances at the end of life, we tend to use words and categories that come from an earlier and outdated perspective.

Much of our language about death and dying conceives of palliative or “end of life” care as a turning away from conventional care. People presumed that a patient would generally get “aggressive treatment” until that was ineffective, and then the patient would turn to “hospice care,” or “palliative care,” which included only symptomatic treatment. This mental model of a transition from one kind of care to another works only if the patient really “turns a corner” and ordinary medical treatment becomes mostly worthless to the patient. This pattern *does* happen with many patients with certain cancers. They go along for many months functioning well and comfortably. Then, cancer overwhelms their bodies; they lose weight, take to bed, develop many more symptoms, and die within a few weeks or months.

Trajectory of Dying for Lung Cancer or CHF



Most of us will not die this way. Instead, we will be disabled for many months or years by diseases such as heart disease, emphysema, stroke, dementia, and even cancers like breast cancer and prostate cancer. Along the way, we will have episodes of serious complications. Any one of these episodes can cause death, and one of them will--but we will not know which one until it is upon us. In other words, most people die of a serious chronic disease, in a week that started just like many other weeks. People now die “suddenly” of long-established illness.

As a society, we are just beginning to learn how to arrange care to serve this population. Hospice is our most dramatic and useful innovation in end of life care. More than half of cancer patients who die while covered by Medicare use hospice. They are treated to unusually

coordinated and comprehensive care, in general. Often, though, patients are not eligible for hospice, since their prognosis is too uncertain until just the last few days. They may not have skilled needs or be homebound, so they get no home care services. Yet, they are terribly sick and fragile. A major challenge for the first decade of this century is to learn to serve this large and growing population that was, until recently, just not apparent to us.

We do have evidence that care at the end of life is improving, and much is being done. I will leave it to my colleagues to tell you about the remarkable work of the Veterans Health Care System, the various organized efforts to educate professionals, and other initiatives. I will focus here on two endeavors--helping the public to learn how to manage end of life issues, and helping the professional care providers learn how to improve their practices.

Last year, about seventy friends of the Center to Improve Care of the Dying helped to produce *The Handbook for Mortals: Guidance for People Facing Serious Illness*. The book offers straightforward common sense advice, helps people to take charge of the end of life, and includes poetry and metaphor to help make sense of the situation as well. Over and over, the response from patients and families has been that the book “gave us the words.” We seem to be so unfamiliar that we simply do not know how to talk about our experiences or to make sense of them. The tables here show two examples of helpful advice to the public from *the Handbook for Mortals*.

Words to Try: For Families, Talking with a Sick Person

When you think you want to say: Try this instead:

- | | |
|--|---|
| • Dad, you are going to be just fine. | • Dad, are there some things that worry you? |
| • Don't talk like that! You can beat this! | • It must be hard to come to terms with all this. |
| • I can't see how anyone can help. | • We will be there for you, always. |

Getting the Most Out of Each Visit With Your Doctor

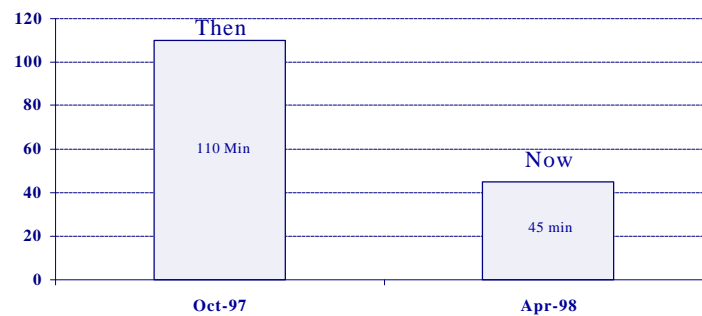
1. Prepare a list of questions and concerns that you want to discuss
2. Consider bringing a family member or friend to help you
3. Bring all of your medicines or a list of them all
4. Set your priorities for the doctor's time
5. Be honest
6. Take notes and repeat what the doctor tells you—in your own words
7. Make contingency plans.

We learned a great deal from producing the *Handbook*. Mainly, we learned that patients and families are desperate for information and insight. Our culture has kept serious long-term illness hidden away. Television shows almost no stories of people living with serious and progressive disabilities and illnesses. So people first encounter these situations as older adults with no experience. I have had so many patients and families turn to me and say something like, “What do I do now?” Over and over, I find that they are not just looking for friendly advice – they really have no idea what people do, or should do, when faced with serious chronic disease. Perhaps federal entities have a role in meeting this need. For example, Medicare’s existing efforts to improve beneficiary information could address serious chronic illness and end of life issues. Public information from the Health Resources and Services Administration and the Centers for Disease Control and Prevention could likewise address these issues.

We also have learned from working with the Institute for Healthcare Improvement and teams from nearly one hundred provider organizations that wanted to improve end of life care. Mostly, we learned that improvements can be made—quickly and effectively. Nearly every team that stayed with the job for a few months made major improvements in something that

matters to patients—within this time. For example, one hospital cut the time a patient had to wait for better pain medication in half.

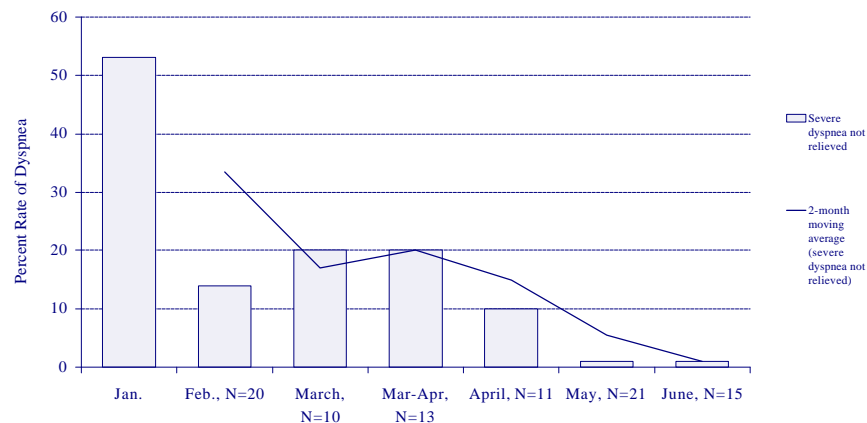
Time Elapsed (in minutes) From Orders to Administration



St. Mary's Health Center: St. Louis, MO

Another program nearly eradicated serious shortness of breath.

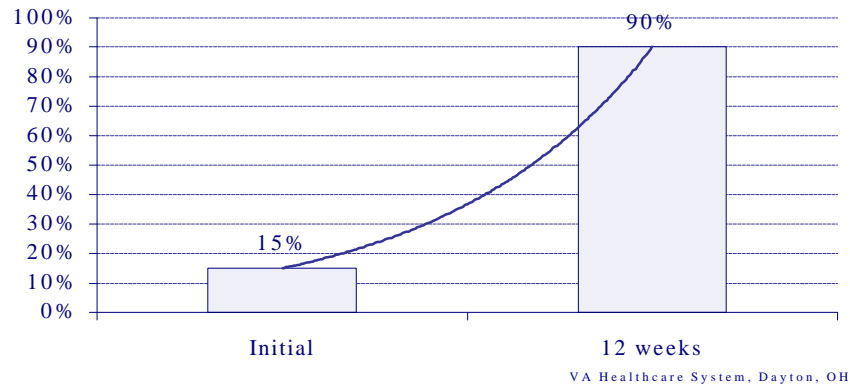
Rates of Dyspnea Not Relieved by End of Shift



Hospice Care of Rhode Island

One program showed that advance planning could cut the rate of frightening episodes to one-quarter of the usual rate. One Veterans Medical Center actually increased the rate of written advance care plans for patients with serious chronic illnesses from 15 % to 90%.

Advance Care Planning Documentation



Nearly all of the programs that worked with heart and lung failure patients cut their rate of hospitalization by 20-50%. One program had trained nurses available to come to the patient's home within half an hour to help with an exacerbation of symptoms. This cut the rate of using emergency rooms to well under half of the previous rate.

How did our collaborating teams get these astonishing results? By using rapid quality improvement methods, which are now well-proven enough that they should be part of the training of professionals. HRSA and AHRQ could be asked to take a role in implementing these strategies much more broadly. So often, what gets in the way of reliably good care is a practice that has become anachronistic, but has not been recognized as such. A caring team that tries out changes fairly quickly finds avenues to get things done right, and efficiently. What is needed to fix a problem in one organization will frequently not be the same as what is needed somewhere else. What we have found, though, is that improvements are possible virtually everywhere.

Some particularly challenging problems will require new insights. Our Center is now working with a few places in the country that are aiming at regional excellence. Think about your own health care—you can't always get what you need in just one care program, as programs are usually defined. At the end of life, this problem becomes exaggerated. Then, you

will usually need good hospital care, smooth transitions to home care and hospice, good nursing homes, and readily available medications. We have found it illuminating to think about what it would take to make care reliable enough that patients can count on it. We have translated this idea into “Promises for Patients,” a set of promises that a good care system should be able to make—from onset of serious illness through to death (even if that runs many years). To make these promises, a physician or nurse would have to know that every part of the care system is reliable. Figuring out how to deliver on that is a major challenge for the next few years.

Making Promises: A Vision of a Better System

- 1. Good Medical Treatment*
- 2. Never Overwhelmed by Symptoms*
- 3. Continuity and Comprehensiveness*
- 4. Planning Ahead, No Surprises*
- 5. Customized Care, Reflecting Your Preferences*
- 6. Family is Part of Care*
- 7. Make the Best of Every Day*

Of course, Medicare has a role in making excellent care widely available. Serious chronic illness has come to be concentrated in old age—now 75% of us die past 65 and covered by Medicare. Medicare provides reasonably well for procedures and hospitalizations, but mostly does not pay for patient/family education for self-care, medications, caregiver supports, or continuity. This pattern is almost perfectly mismatched with the needs of those who face dying. We could really benefit from a few years of substantial innovation and evaluation, learning how to build a rather different care system that was tailored to our new demographics.

Indeed, we only have a few years to learn. The numbers of people who are very sick at the same time will continue to rise for the next three decades, eventually tripling from the present rates. If we continue to do no better than we do now, the suffering will be overwhelming, and the costs will be crippling. If we learn to do better and to deploy our knowledge effectively, we could instead have an end of life that is comfortable and meaningful in a care system that is sustainable.

This fall promises to see a substantial increase in public attention to end of life issues. Bill and Judith Moyers will have a four-part series on PBS in early September. Many magazines and newspapers are planning stories loosely linked to this, including a multi-page insert in *Modern Maturity*. The nation's public libraries and hospices, for example, will be sponsoring a large number of community meetings on the topics raised. The National Coalition for Health Care and The Milbank Foundation will be releasing separate reports on what can be accomplished by provider organizations today. Improving end of life care may well be a very important issue this fall! Our group has established a website that will help those from provider organizations who might be interested in improvement: <http://www.medicaring.org>. We will provide initial information and guidance, refer to others who offer help in specific areas, and offer follow-up information as opportunities arise. We will help your offices to answer public inquiries as well, including by putting you in touch with the growing array of concerned experts and proven improvement activities.

Significant and enduring improvement is within our grasp. All it takes is leadership and vision and a lot of hard work. The Congress, our country's leaders, could provide the leadership and vision. We could initiate substantial efforts to learn together how to serve those coming to the end of life. All of us have a stake in this, and all of us will reap the benefits of learning to do it right!

To improve the end of life for patients and families, Congress should:

- Encourage innovation in providing services, and insight as to what will work
- Support learning, professional and public
- Evaluate policies, existing and proposed, by effects on those with serious chronic illness, and their caregivers
- Aim to develop coherent, efficient, and effective strategies to serve this population -- within a few years"

Attachments:

- Promises to patients
- Twenty things clinicians could do
- Getting started—improvement activities for providers
- The Agitator's Guide